

# Post-stroke peer-support groups Research report

An investigation of the Stroke Association's peer-support groups before and during the Covid-19 pandemic

---

*Mark Tarrant, Ruth A. Lamont, Laura Hollands, Luke Mounce, Sarah G. Dean, Chris Code, Jess Bollen, Amy Sanders & Raff Calitri*

April 2022

# Contents

## Contents

Executive summary .....	3
Summary of <b>main findings</b> .....	3
Study limitations .....	5
Conclusion .....	5
About this report.....	7

# Executive summary

**Stroke** is a leading **cause of** long-term **disability**. After a stroke people may have difficulties with their movements, **emotions** and **energy levels**. These issues **can affect** how well they can perform their daily tasks and how well they feel in themselves, otherwise known as their wellbeing. People may also find it **difficult to make and keep new relationships**. Stroke survivors may be **lonely**, have **lower self-esteem, and poorer wellbeing**. **Support after a stroke is essential** to help people **adapt** and to **live well** with the effects of their stroke.

The main place for **stroke support** is the **Stroke Association** who have more than 200 **support groups across the UK**. **Before the Covid-19** pandemic, these groups offered people who had had a stroke a **place to meet up** and get to know each other. The groups offered different **activities** for members. Research has shown that people often feel better about themselves and less lonely **after taking part in a group**.

**This project** looked to further **understand how groups** helped **stroke survivors**. We used **two large surveys** (a total of 839 people from 118 separate support groups took part) and **interviews** (20 people took part) with group members and volunteer leaders. Through this research, we **measured stroke survivors' loneliness and wellbeing**. We looked at **reasons why taking part** in a support group **might influence how well people feel about themselves**: in particular, we looked at their sense of connection to their stroke support group (known as **social identity**) and how this may have **contributed to loneliness and wellbeing**.

We **originally planned** to conduct the **survey at two time points** to record how **experiences** of the stroke support **groups, and health, changed over time**. However, the **Covid-19** pandemic **stopped this**. The **pandemic** meant that we had to **change** our plans. It gave us the chance to **understand how the pandemic affected** stroke survivors' **experiences** of the **peer-support programme**.

The main **findings** from the project are **summarised below**:

## Summary of main findings

### Pre-pandemic survey

- **116 group leaders** (out of 215) **gave out a survey** to their groups. **579 people** from 84 groups returned a survey.

- **47% of stroke survivors reported often feeling lonely.** This is **higher than loneliness** in the **general population**.
- Stroke survivors had an **average wellbeing score** of 22 (out of 35), which was **similar to the national average** (24). Scores lower than 20 show that people might have depression or anxiety.
- People who **felt connected** and **supported by their group** felt less lonely.
- People who **felt connected** and **supported by their group**, and who also felt they were quite **independent**, had **higher wellbeing**.
- These findings showed that **it is important to feel part of the group** as it may **help** stroke survivors to **have better wellbeing**.
- **People are more likely to feel part of their support group** if they see **themselves as a stroke survivor** or belong to other groups already. Groups **meeting regularly** can **help people** feel ready to **connect to their support group**.

#### Pandemic survey

- **260 participants responded** from 118 groups. **Some group members** and **volunteers** took part in a telephone **interview**.
- **Levels of loneliness** in the pandemic survey **were similar** to the **pre-pandemic** survey - **44% of respondents** reporting **often feeling lonely**.
- **Overall, wellbeing** and **connection to the group** was **very similar** between the **pre-pandemic** and **pandemic** surveys.
- **87% of group members** had some **contact with their groups** during the pandemic.
- Main **contact methods** for the groups were **telephone** calls, **emails** and **text-based messaging**. This let group members keep a **sense of connection to the group**.

#### Interviews

- **Interviews** with stroke survivors **showed that the support groups were important**. People talked about how being seen as similar to others was a **key part of their positive experience of the group**. These experiences seemed **more noticeable** during the **pandemic** when face-to-face group interaction was not possible.
- People talked about how **stroke groups provided** a way to make **contact with others**. This **need for contact stayed during the lockdown** and when **groups moved onto Zoom**.
- Stroke groups not only **provided support** for stroke survivors but was also a place where some **partners and carers** could connect and support each other.

- Stroke survivors were generally **positive about groups moving online** and being contacted during the pandemic by volunteers and session leaders, but **others thought more could have been done.**
- **Some people found it difficult to get online to meet with the groups.** This was sometimes because they **didn't know how to use the equipment**, or because **they needed help getting set up** from others who couldn't always be around when the groups were meeting

## Study limitations

**People who took part in the research chose to go to the Stroke Association peer-support groups and wanted to take part in the research. The findings are only about these types of people and might not be the same for other stroke survivors. Completing the survey online may have meant that** stroke survivors who have access and use of the internet were more likely to take part. **These people may also be better at keeping in contact** with others.

- **Other social groups** that people belonged to during the pandemic **were not looked at in this research.** These other groups may have become more important for participants.
- **Groups may not be suited to all stroke survivors. Fitting into a group may be hard for new members. People's early experiences and 'first impressions' of the group are therefore important.**

## Conclusion

This project **reports on stroke survivors' thoughts and feelings about the Stroke Association's peer-support group programme.** The research was carried out just before the Covid-19 pandemic, when **groups were meeting in-person, and during the pandemic when in-person meetings had to stop.**

The project showed that:

- **Peer support groups are important** as the **people who go to groups and feel connected** have **lower levels of loneliness** and **improved wellbeing**
- **Meeting regularly**, such as once a week **helped people feel ready to connect** to their groups
- **Feeling a connection** to groups can be **helped if**; people **see themselves as a stroke survivor**, the **same people attend the meetings** (almost) every time, they have a **good experience** when they join the groups (e.g. new members could be buddied up with an existing member)
- During the pandemic **group leaders were good at keeping groups going** by setting up **online meetings.**
- For stroke survivors that **couldn't use the internet** group leaders and volunteers generally **got in touch** with these people by **phone, text based messages or even newsletters.**
- The surveys and interviews made it clear that **stroke survivors appreciated** how well **stroke groups adapted** during the pandemic however **some people did feel more support could have been provided**

Finally, the project has highlighted what might make it more likely for stroke survivors to get involved with support groups. **It has found out ‘who’ is more likely to grow a strong sense of connection to a stroke support group – and when they might do this.** The current study has found several areas that may benefit from targeted action, both at a structural, organisation level, and managing group members’ experiences of the group.

## Project outputs

### *Conference seminar presentations:*

International Conference on Social Identity and Health ‘Taster Event’, Nottingham (2021). *“If you build it they will come”. Applying the social identity model of behavior change in community and clinical interventions.*

International Conference on Social Identity and Health ‘Taster Event’, Nottingham (2021). *“Social Identity and loneliness: Results from a national cross-sectional survey of peer support groups for stroke”.*

Nottingham Trent University, School of Psychology (2020). *“If you build it they will come”. Applying the social identity model of behavior change in community and clinical interventions.*

### *Published articles:*

Lamont, R. A., Calitri, R., Mounce, L. T. A., Hollands, L., Dean, S. G., Code, C., Sanders, A., & Tarrant, M. (2022). Shared social identity and perceived social support among stroke groups during the COVID-19 pandemic: Relationship with psychosocial health. *Applied Psychology: Health and Well-Being*. <https://doi.org/10.1111/aphw.12348>

We are currently preparing other aspects of the project for publication.

# About this report

## The project

This research **project was formally known as** the '**Community Groups for Post-Stroke Support**' study at the **University of Exeter**, UK (Twitter: [@CoGS\\_study](https://twitter.com/CoGS_study)).



The **CoGS** study was **funded** from the **National Lottery Community Fund**, with **Nesta**, as part of their support for the **Stroke Association's** growing **support network**.

**Ethical approval** was granted by the **University of Exeter** College of Medicine and Health **Research Ethics Committee** (ref: Oct19/B/223).

## Contributors

**All researchers are from the University of Exeter. The study was led by Associate Professor Mark Tarrant (principal investigator)**, Dr Ruth Lamont (project manager), and Dr Raff Calitri (co-investigator), supported by: Laura Hollands (PhD researcher), Dr Luke Mounce (co-investigator), Professor Sarah Dean (co-investigator), Professor Chris Code (co-investigator), Dr Jess Bollen (researcher) and Dr Amy Sanders (co-investigator).

The **project was helped** by a **group of people with experience of stroke and leading a support group**. The **group helped by checking the survey and interview plans**, and gave **advice on contacting stroke groups**. They continue to support the project as it is written-up and shared with others.

## With thanks to

The authors would like to **thank the people that took part** in this research. This research would not have been possible without them. We would also like to **thank our group of people with experience of stroke for their help** with this work. We are also hugely **grateful to Beth Scrimshaw and Jane Tooke at the Stroke Association** for their enthusiasm and help.

Sarah Dean's and Mark Tarrant's time is partly supported by the National Institute for Health and Care Research Applied Research Collaboration South West Peninsula. The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health Research or the Department of Health and Social Care, UK.